



CARNITINE UPTAKE/TRANSPORT DEFICIENCY

(CUD/CTD)

FAMILY FACT SHEET

What is a positive newborn screen?

Newborn screening is done on tiny samples of blood taken from your baby's heel 24 to 36 hours after birth. The blood is tested for rare, hidden disorders that may affect your baby's health and development. The newborn screen suggests your baby might have CUD/CTD.

A positive newborn screen does not mean your baby has CUD/CTD, but it does mean your baby needs more testing to know for sure.

You will be notified by your primary care provider or the newborn screening program to arrange for additional testing.

What is CUD/CTD?

CUD/CTD affects an enzyme needed to break down fats in the food we eat, so they can be used for energy and growth. In CUD/CTD, the enzyme used to break down fats is missing or not working properly.

A person with CUD/CTD doesn't have enough enzyme to break down fat for energy. Carnitine helps the body make energy from fats and also helps the body use stored fat.

CUD/CTD is a genetic disorder that is passed on (inherited) from parents to a child. The mother and father of an affected child carry a gene change that can cause CUD/CTD. Parents usually do not have signs or symptoms, or even know they carry the gene change.

What problems can CUD/CTD cause?

CUD/CTD is different for each child. Some children with CUD/CTD have few health problems, while other children may have very serious complications.

If CUD/CTD is not treated, a child might develop:

- Sleepiness
- Behavior changes (such as crying for no reason)
- Feeding problems
- Seizures
- Coma

It is very important to follow the doctor's instructions for testing and treatment.

Some people with CUD/CTD have no obvious symptoms. This is why mothers of babies with positive screens need testing. Sometimes, a baby has a positive screen because the mother has a hidden form of CUD/CTD.

What is the treatment for CUD/CTD?

CUD/CTD can be treated. Treatment is life-long and can include:

- Carnitine to help the body make energy and get rid of harmful toxins.
- Frequent meals/snacks – a dietician will help you set up the best diet for your child.
- Low fat/high carbohydrate diet – a dietician will help you learn what foods can be eaten.

Children with CUD/CTD should see their regular doctor, a doctor who specializes in CUD/CTD, and a dietician.

Prompt and careful treatment helps children with CUD/CTD live the healthiest lives possible.

Michigan Resources and Support

Michigan Newborn Screening

Nurse Consultant

Toll-free: 1-866-673-9939

newbornscreening@michigan.gov

Children's Hospital of Michigan Metabolic Clinic

Toll-free: 1-866-442-4662

Children's Special Health Care Services

Toll-free: 1-800-359-3722